# Politics of Labelling
## Case Study One - Part A

The following scenario was taken from Herb Lovett's book, *Learning to Listen.*

In opening his book *Learning to Listen*, Herb Lovett describes an encounter with Maureen, a woman with an intellectual disability. Her service team

had approached him for advice on the development of a behaviour program.

## Current Situation

*Maureen is in her early 30's and has an intellectual disability. She has*

*lived most of her life with her mother, but she became too frightening for*

*her mom. When she got angry she would break things and sometimes she would hit her mother. For a while she had lived with a boyfriend who had been violent and seriously abused her. Now she was living at a nearby developmental centre where she was being given large doses of anti-psychotic and anti-convulsant medication that made her drowsy.*

Maureen was not interested in the *piecework offered her every day, preferring instead to talk about her fantasy that two co-workers were having an affair. At times she could become agitated and abusive for no apparent reason, screaming or hitting the people around her. For a day's good behaviour – not annoying or hurting people – she could earn enough points to "buy" two cans of caffeine-free diet soda. She could have only diet cokes because the staff decided she was over weight and shouldn't drink caffeine.*

Herb Lovett asked the team, *If Maureen died tonight who would care? Someone said her mother probably would. "Anyone else?" I asked. The group thought about it and decided, "Not really".*

## Discussion Points

- Identify the issues facing Maureen and her support team.

- Discuss ideas for resolving these issues including the behavioural issues.

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**Politics of Labelling**
**Case Study One–Part B**

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Lovett identified the differences between what we know about Maureen and what we do to support her. He states: s*o this woman who has no home, whose one emotional relationship with someone other than her mother has been abusive, who makes about $5 per week and who has no friends is difficult to be around. In the face of all this – by way of comfort and assistance – she is told that if she is "appropriate" she can earn two cans of diet cola a day.*

He further stated that: *knowing her plight as a homeless, poor and battered woman, would ordinarily move people to think in terms of getting her some emergency money, a reliable income, and a safe home. Instead, because of her labels as "mentally retarded" and "emotionally disturbed," she is seen as needing treatment . . .*

*Her behaviour program – primitive as it is – was treating her behaviour as a symptom that could be made to disappear with proper treatment. However, Maureen's team best understood her as a person as a woman who had a hard life. When asked to explain who they thought she was they accurately described Maureen as an abused, estranged and oppressed woman whose differences had led her to a life of poverty, uncertainty and profound loneliness. Their confusion about her came because they had fallen into the gulf between the way they knew her as a person and the way they reacted to her as a* **client**.

**Lovett states that** *I took a long time to realise that people labelled "retarded" had very different lives because of this label we psychologists had given them. "Those people," who might need help in ways large and small, almost always pay for the help they need with their freedom, their dignity and a general loss of control over their own lives.*

**Discussion Points**

- Discuss the issues raised by Lovett in relation to the ideas raised in the previous group discussion.

- Discuss the concepts raised by Lovett and the implication of having an intellectual disability to how we interpret a person's behaviour. Are we more likely to see their behaviour as an individual trait and not as a consequence of social of welfare issues?

**Defining Challenging Behaviour**

Emerson (1995) Defines challenging behaviour as:

*Culturally abnormal behaviour/s of such intensity, duration, frequency that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of or deny access to ordinary community facilities*

Using this definition, identify other sections of our society whom it could be said exhibit challenging behaviour and the solutions adopted by the community in response to the behaviour eg. heroin addicts – safe-injecting rooms, young male drivers – shock ads, higher insurance premiums – driver eduction in schools, domestic violence – counselling, etc.

How would the interventions differ if each of the people identified in the previous section also had an intellectual disability?

*It is clear that differing levels of staff tolerance do mean that different definitions prevail in different settings. I once spent a considerable amount of time trying to persuade the manager of an Adult Training Centre that setting off the fire alarm deliberately two years previously was not sufficient in itself to identify someone as showing challenging behaviour. In the same round of interviews, a member of staff in hospital who had been punched in the side of the head by a resident the previous week argued that he should not be identified as challenging because she had been aware of what might happen and had thoughtlessly been standing in the wrong place*. **The Size of the Problem (Hazel Qureshi)**

*Sexuality and sexual expression are often denied to people with disabilities. When sexual behaviour is exhibited it can be defined as challenging behaviour by carers.* **Pauline Williams**

Discuss problems relating to the subjectivity of the term, challenging behaviour eg: values of the person attributing the label, lack of consistent definitions, the lifetime

implications of the label etc

**Handout 1**

## Traditional Accommodation Models
## A Critique

Currently in Victoria a traditional facility-based model is the common form of service delivery for people with ongoing needs. Government and non-government agencies manage a range of accommodation options, which may include congregate care facilities, group homes and some smaller residences. Programs and support provided by the agencies are typically based around the accommodation options they offer rather than around the individual.

Services and programs provided by facility-based agencies are often based on the principles of least restrictive environment. Agencies carry out an assessment of an individual's needs and abilities and match them to an accommodation option which best meets these needs. The accommodation options are usually limited to those managed by the agency. People with the most severe disabilities are usually placed in the "most restrictive" accommodation, the theory being that as people acquire skills they will move along a continuum into more independent settings. In reality people with support needs often end up living in one style of accommodation for years, only moving as a result of administrative or behavioural issues.

The Centre on Human Policy (Syracuse University N.Y.) identifies the following problems with the continuum concept:

- People with severe disabilities get relegated to the "most restrictive" end of the continuum.
- The most restrictive placements, such as institution, are not necessary
- The continuum implies that people need to leave their homes every time they acquire new skills
- The most restrictive placements do not prepare people for the least restrictive placements
- The continuum approach concentrates resources at the most restrictive end instead of towards typical homes
- The continuum concept confuses restrictions of people's rights with intensity of their support and service needs
- The continuum directs attention to physical settings rather than to the services and supports people need to be integrated.

The facility-based approach usually includes a process whereby the individuals and their families meet with the agency and develop an Individual Program Plan based on individual needs and wishes. However, there is a limit to the options available for a person with a severe disability or labelled as having a challenging behaviour. Accommodation options are usually limited to congregate care settings or group homes.

The administration and staffing practices of traditional service agencies also restrict the options available to people. Because many group homes do not have staff during the day people must attend full-time day programs. This is an example of administration and resource issues impacting on the ability of an agency to offer real choice.

**Group Homes**

When people with ongoing needs move into the community from an institutional setting it is usually to a group living

situation. Group homes have enabled many people to move out of institutions (Kinsella 1994). However, many agencies are now coming to realise that in some ways they continue to congregate and segregate people with an intellectual disability.

Hornsby Challenge (Van Dam & Cameron) identified the following problems with group homes:

- **Incompatibility** – people are expected to live for many years with three or more people with whom they may have nothing in common. They are expected to cope and behave "appropriately" in this living situation no matter what differences and falling out they may have with other people living there.
- **Sharing** – sharing can be very difficult for any adults living together who have to share facilities in a house.
- **Limitations on expression of individuality –** group homes tend to operate on a structured basis. In a group home people are expected to shop and eat together and very often to recreate together.
- **Needs of the group take priority –** the ability to exercise individual decision making is also severely limited because the needs of the group come first.
- **Fixed and rigid routines –** routines in group homes tend to be very fixed and bureaucratic because they must cater to the needs of the group rather than the individual

The problems described above can lead to people becoming unhappy with their living environment. Because they have no control of the situation they will look for ways to express their discontent. Such expressions of discontent are usually labelled as behaviour problems (Van Dam, Wunsch and Hugill)

It is important to recognise that the group home model has effectively provided accommodation in the community for many people who have been labelled as having challenging behaviour and whom it was previously thought would be institutionalised for life. It is through the group home approach that governments and services agencies have been able to demonstrate to the community and families that people with challenging behaviour can live in the community. But as with all models of service delivery it is important to recognise the limitations of providing only one style of service delivery. There is a need to work to improve and change the way we deliver services so that true community inclusion can occur for **all** citizens.

*It's hard to see how arbitrarily assigning people to any living arrangement could ever bring them happiness. Indeed, as we have learned, group homes merely continue the history of isolation and stigma* **(Lovett Herb 1996)**

**Handout 4**

## **Hornsby Challenge**
## **(New South Wales)**

The information contained in this outline was obtained from:

*Beyond Group Homes; Conference paper* Trudy van Dam & Fiona Cameron-McGill

*Behaviour Management – Don't Treat Me That Way* Trudy van Dam & Fiona Cameron-McGill

*Developing Relationships – That's What Friends are for!* Trudy van Dam & Fiona Cameron-McGill

### **Background**

Hornsby Challenge is a community-based organisation, which was responsible for facilitating the closure of *Mount Own* aninstitution for women with an intellectual disability**.** Mount Own was established in 1964 to provide care for 57 women. The women who lived there had a range of support needs varying from very high to quite low. In 1985

Hornsby Challenge began the process of moving the women from the institution into community based accommodation. This process was completed in 1987.

**Methodology**

Initially the women moved into 3 to 4 bed group homes. Hornsby Challenge, which is committed to fostering community connections, sought to avoid the segregation and isolation, which can accompany deinstitutionalisation. They became aware that the group home style of living not only did not suit everybody but also continued institutional practices. It was felt that the provision of only one type of housing model was hardly conducive to fostering a flexible and responsive service, which recognised individual's needs and preferences. Hornsby Challenge contended that the expression of tensions and the problems which can arise as a result of living in a group home may lead to individual being labelled as having a behaviour problem.

Hornsby Challenge now offers a range of supported living options based on the needs and wishes of the individual. Hornsby Challenge accepts that while some people may choose to live in a group home, a range of accommodation options should be offered for *people who want or need other living arrangements.* Hornsby Challenge has developed a broad range of accommodation options required to meet the needs of a diverse group of people. Accommodation options provided by Hornsby Challenge include:

- groups of three people living together
- sharing with another person without a disability
- sharing with a person with a disability
- living alone
- boarding with a family
- living in a family home
- supporting people who now need nursing home care

Hornsby Challenge claim that a series of attitudinal and structural changes are needed to provide an individualised accommodation service including:

- considering what works best for the person
- not being constrained by past or current options available
- adopting flexible service structures and staffing
- flattening management structures
- flexibility in provision of housing

- separating housing and support issues
- flexibility in staff duties
- making efficient and effective use of resources
- focussing on skill development
- use of generic services
- enlisting support from family and friends

## Behaviour Support

To provide support for people who have been labelled as having challenging behaviour Hornsby Challenge has developed a *holistic approach to behaviour management.* The adoption of the holistic service model has led to a sustained decrease in the instances of challenging behaviour, institutional behaviours, in particular, have completely disappeared eg. rocking, walking in circles etc

## Conclusion

Hornsby Challenge provides a practical and well thought out model of service delivery.

Both the accommodation and services they offered are designed to meet the unique needs and lifestyle choices of individuals. Hornsby Challenge has successfully provided support for people with ongoing needs to live in the community. The evolution of Hornsby Challenge has been a gradual one and was achieved without additional funding. The changes were financed through the redistribution of resources, increasing the use of generic services, and expanding support and community networks.

Hornsby Challenge believes that by restraining growth they have been able to maintain a responsive and effective supported living service. They have now decided to focus their attention on disseminating information, providing support and acting as mentors to other service agencies wishing to move towards supported living.

**Handout 5**
**Case Study**
**The following Case Study provides an example of problem resolution using the principles of supported living**

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Brenda had a range of difficult behaviours around throwing objects and ripping her clothes. She lived with two men whom she quite liked, she had regular contact with a supportive family and worked five days a week.

We began to understand that Brenda tended a feel over stimulated by crowds and anything more than two people in a room constituted a crowd for her. She found living with two other people and having to share staff difficult (even though she quite liked the two people she lived with) It has been identified that Brenda responds best to older women.

Obviously, her living situation needed to change (remembering our principle "what does the person want? Can we give it to them? The answer was yes!)

The urgent preventative solution was to radically change her environment to a living situation that actually suits who she is as a person. So four years ago we found her a two-bedroom unit and advertised for an older person to be a live-in companion: specifically to share her unit and provide some evening support. Staffing was provided on a one-to-one basis at other times and potentially stressful crowded settings were avoided.

By meeting Brenda where she is at and with what she can cope with at each point in time, we have slowly been able to assist Brenda to cope better. Last year she went to a noisy Christmas party at the integrated workplace where she is employed and had a lovely evening with about a hundred other workers.